

White Paper

Olmstead Workgroup

November 6, 2000

PREFACE

The U.S. Supreme Court's ruling in the *Olmstead v. L.C.* case in 1999 has provided a mandate for States to review their systems of care for persons with disabilities. The North Dakota Department of Human Services (DHS) has responded through an incremental process designed to carefully identify and review the current status of the issues requiring attention in meeting the intent of the *Olmstead* Decision. The following steps were identified and completed:

- ! Carol Olson, Executive Director of the North Dakota Department of Human Services, appointed an internal workgroup to review the *Olmstead* Decision and make recommendations on further action. This group consisted of representation from the Divisions of Aging Services, Children and Family Services, Disability Services – Developmental Disabilities Unit, and Mental Health and Substance Abuse Services as well as representatives from Medical Services, the Developmental Center, the State Hospital, the regional human service center directors and the Legal Advisory Unit.
- ! It was determined by the workgroup that regional information meetings needed to be held with consumers, families, advocates, and providers in the areas of mental health, aging, developmental disabilities and physical disabilities. Goals established for these meetings included:
 - * Clarifying the content and nature of the *Olmstead* decision
 - * Updating attendees on the current status of institutional and community based services for various populations in North Dakota
 - * Soliciting discussion and input from attendees on areas they see as needing attention.
- ! In August of 2000, four meetings were held via the North Dakota Interactive Video Network (IVN). More than 200 persons attended these meetings throughout the state. Discussion occurred at each meeting and the workgroup answered participants' questions. In addition, a brief survey was available for attendees to complete. The surveys were gathered and analyzed by the workgroup.
- ! The efforts of the workgroup culminated in a White Paper for the Executive Office of the North Dakota Department of Human Services outlining background information, workgroup activities, and recommendations for future action.

It should be noted that in a letter to State Medicaid Directors, the Health Care Financing Administration (HCFA) suggested a planning process to address the *Olmstead* decision. HCFA's recommendations, however, were not binding nor mandated. In light of this, the workgroup chose to develop its own process to carefully and fully assess the issues. It should also be noted that the workgroup strongly recommended at the outset, to approach the *Olmstead* decision in a joint, comprehensive fashion to avoid what some other States had noted as "pitting one disability population against the other" for resources and action.

LEGAL BACKGROUND

The Olmstead Decision: In the case *Olmstead v. L.C.*, two institutionalized women sued the State of Georgia claiming they should have been moved out of the facility and instead treated in the community. The United States Supreme Court found that society has tended to isolate and segregate individuals with disabilities. The Court found that such segregation can be a form of discrimination based on disability.

The U.S. Supreme Court held that states are required to provide community-based services in certain circumstances to avoid violating the mandate of the Americans with Disabilities Act (ADA). The Court held that States must provide community-based services when three criteria are met:

1. The State's treating professionals determine community placement is appropriate;
2. The affected client does not oppose the transfer from an institution to a community placement; and
3. The placement can be reasonably accommodated taking into account the resources available to the State and the needs of others.

When these three criteria are met, States are required to make "reasonable modifications" to avoid discrimination. A "comprehensive working plan" can show that a State has maintained an appropriate range of facilities and services for placing qualified persons in non-institutional settings. The Court also found that a State can show compliance with the ADA if the State has a waiting list for community-based services that moves along at a "reasonable pace" not controlled by the State's endeavor to keep its institutions fully populated. However, the Court was careful to point out that a State's obligation is not boundless. States may lawfully resist modifications that entail a "fundamental alteration" of the State's services and programs.

The *Olmstead* decision leaves several areas open to question, such as:

1. What is a "reasonable accommodation" versus a "fundamental alteration?"
2. What is a waiting list and when does it move along at a "reasonable pace?"
3. What constitutes an "institution?"

ARC v. STATE OF NORTH DAKOTA: In 1980, the Association for Retarded Citizens (ARC) filed a lawsuit against the State of North Dakota alleging constitutional violations on behalf of a class of individuals with developmental disabilities. The suit sought less restrictive, community-based alternatives for care of these individuals than the State institutions in which they then resided.

In reaching a decision, the Federal court noted that there was little consensus among the experts who testified on what constitutes an "institution". The court instead focused on requiring the state to ensure that it cares for individuals with developmental disabilities in the "least restrictive setting" possible. The court acknowledged that institutions could not be

entirely done away with as there will always be some number of people who, because of the complexity of their needs and severity of disability, will have to be congregated for care.

For the past twenty years and long before the *Olmstead* decision, the North Dakota Department of Human Services has been working to ensure that persons with disabilities are being cared for and treated in the least restrictive environment possible.

INSTITUTIONAL-BASED SERVICES

NORTH DAKOTA STATE HOSPITAL: For the past 50 years, the North Dakota State Hospital has shown a gradual decrease in the average daily census of hospitalized patients from over 2,500 patients in 1950 to approximately 160 today. A number of factors contributed to this evolution including the availability of the first psychotropic medications, establishment of the eight regional human service centers, and more admission screening.

During the 1990's through to the present day, a dramatic shift occurred away from a more centralized hospital model to one that includes a wider array of community-based services. As a result, the hospital's patient population significantly decreased. This began during the 1989 – 1991 biennium when a change in State statute required all voluntary admissions to the State Hospital to be prescreened at one of the regional human service centers. Consequently, more individuals were diverted to community services. The census at the hospital decreased from over 500 patients to approximately 275 patients. Because of this decrease, hospital patient care areas were reduced from 17 to 10 patient care areas. Greater emphasis was placed on case management and other community-based options.

The daily patient census continued to decline during subsequent bienniums because of improved screening criteria and an increased focus on shortening the length of stay. The establishment of an 8-bed transitional living facility on the hospital's campus allowed for a less restrictive level of care for individuals who had reached maximum benefit of hospitalization but awaited placement in other community facilities. A strong emphasis from the Department of Human Services was placed on integrated case management, serving the whole person with home and community based services where possible. In order to assist the human service centers with developing new community services, hospital funding was shifted to the human service centers.

During the 1997 – 1999 biennium, two additional patient care areas in the hospital closed. A chemical dependency treatment patient care area was able to be closed due to increased community service provision, and a geropsychiatric patient care area closed when patients were transferred to a specialized community program in Valley City. This reduced the total number of hospital patient care areas to eight.

In further expanding treatment options, the chemical dependency service established a residential level of care to decrease costs for patients who do not require intensive medical services. A 30-bed revocation program using hospital addiction professionals was also established at the Jamestown Law Enforcement Center in collaboration with the Department of Corrections.

A change in North Dakota law, requiring that all potential admissions to NDSH (both voluntary and involuntary) be prescreened by one of the eight Regional Human Service Centers, became effective in July of 1999. State Hospital and human service center staff met again with local stakeholders in each region to provide education about the change in screening requirements as part of a continuing focus on providing community-based care.

In the current biennium, the State Hospital is budgeted for an average daily population of 165 patients. Actual census has ranged from approximately 155 to 170 patients. Hospital staff continue to collaborate with human service center staff in further developing needed community based services. Overall, diversification of levels of care and focus on specialized services has occurred simultaneously.

The State Hospital continues to provide services for individuals whose needs exceed available community-based services and focuses on minimizing the length of stay in order to facilitate prompt return to the community.

NORTH DAKOTA DEVELOPMENTAL CENTER: Since the 1960's – when the Developmental Center had over 1,200 residents between its two facilities in Grafton and Dunseith – the resident census has declined to the current level of approximately 149 people. This decrease was a direct result of the availability of the first psychotropic medications and increased community-based supports including the establishment of the regional human service centers and a growth in the number of private providers. In fact, because of these factors the Dunseith operation was closed in December of 1987 leaving the Grafton facility as the sole, specialized residential facility.

As mentioned earlier, the ARC v. Olson (1982) lawsuit prompted improvements in residential options. The resident census dropped to 250 by 1989. The Center received accreditation from ACMR/DD in 1989 – now referred to as the Council – and since then has consistently received the highest level of accreditation given to an “institutional” setting in the United States.

The period from 1989 to the present has seen a dramatic clarification of the Developmental Center's role in the service system. Private service providers and human service centers in every region continued to encounter people requiring assistance from and/or admissions to the Developmental Center. This has made clear the role for a “Safety Net” service for people with cognitive impairments in North Dakota when no other setting is appropriate or available.

During the 1990's a number of programs were initiated, aimed at further reducing the number of admissions to the Center while enhancing available services. For instance, the ERIC (Evaluation, Respite, Intake, and Consultation) unit was established to allow more rapid response to regions referring for admissions and to provide informal intervention to prevent admissions. This was later replaced with the new, comprehensive CARES (Clinical Assistance, Resources, and Evaluation Services) program, which was established to ensure high quality and systematic assistance to private providers and human service centers.

Today, the North Dakota Developmental Center continues to provide needed services and supports to people enabling them to be viable citizens in their communities.

COMMUNITY-BASED SERVICES

DEVELOPMENTAL DISABILITIES SERVICES: North Dakota was one of the first States to receive a Medicaid Home and Community Based Care waiver for persons with developmental disabilities. In 1984, the first year of the waiver, 68 people received home and community based care services. Since then, there has been steady growth in the Home and Community Based Care waiver program, with 1,875 people choosing this service option in 1999.

In 1982, the majority of persons with developmental disabilities receiving residential supports received those supports in settings serving sixteen or more persons, with the fewest number of persons receiving their supports in settings serving six or fewer persons. In 1999, the majority of persons with developmental disabilities receiving residential supports received those supports in settings serving six or fewer persons, with the fewest number of persons receiving their supports in settings serving sixteen or more persons.

Not counting the Grafton Developmental Center, there are 99 community group homes across North Dakota licensed to provide services to persons with developmental disabilities. Of these, 86 are licensed to provide services to 8 or fewer persons, with 32 licensed to provide services to 6 or fewer persons. Additionally, over 1,000 persons are supported in their own home or apartment through individual services offered by licensed providers, county social service boards or qualified service providers. In the area of services and supports to families, early intervention services are available for infants with a developmental delay, family subsidy payments are available to assist with the extraordinary cost of caring for a child with a developmental disability, and family-centered services are available to support the primary caregiver in meeting the health, developmental, and safety needs of the eligible individual.

AGING SERVICES: Services under SPED (Service Payments for Elderly and Disabled) and the Medicaid Waiver for the Aged and Disabled were implemented in 1983 to reduce the reliance on use of institutional care by offering quality services in an alternative setting. Through the development of a consumer-focused, affordable social model delivery system, services are provided for the aged and persons with physical disabilities, who, because of their impairments, have difficulty completing activities to enable them to remain in their own home.

A targeted Medicaid waiver for persons with traumatic brain injury (TBI) was implemented in 1994; Expanded SPED was implemented in 1995, as a companion piece to the Basic Care Assistance Program.

The number of unduplicated recipients served under the SPED Program has grown from 356 (FY84) to 2,044 served in 1999. Expanded SPED served 242 clients; the Medicaid Waiver for Aged and Disabled served 347 clients; and the Medicaid Waiver for Traumatic Brain Injury served 14 clients in 1999.

Available services include: Case Management, Homemaker, Personal care, Adult Family Foster Care, Respite Care, Adult Day Care, non-Medical Transportation, Chore Services, Emergency Response System, Environmental Modification, Specialized Equipment, Family Home Care.

There has been a continual increase in the total number of individuals who receive services in their home and/or community. In FY 84, the first year of implementation, the total number was 395. In 1995, the total was 2,086; during the past year, the total was 2,647 individuals served.

The Older Americans Act of 1965 provides funding for home and community-based services to individuals age 60 and older. Individuals with disabilities who are under the age of 60 are eligible to receive congregate and/or home-delivered meals if he/she resides in a housing facility that has a congregate meal site or if he/she resides in a non-institutional setting with a person who is 60 years of age or older. Available services include: Congregate and Home-Delivered Meals, Outreach, Health Maintenance, Transportation, Chore, Information and Assistance, Vulnerable Adult services, Legal Services, Senior Companion Services, Home Injury Prevention, and Education and Advocacy. Last year the total number of individuals served was 25,339.

MENTAL HEALTH AND SUBSTANCE ABUSE SERVICES: Community-based mental health and substance abuse services in North Dakota – targeted to adults diagnosed with serious mental illness (SMI); adults with emotional disorders requiring short-term, acute mental health services; children diagnosed with serious emotional disorders (SED); and adults and children with substance abuse problems – are provided by the eight regional human service centers. Services are provided directly by the human service center, through a contract with a private provider, or referred to another provider in or out of the region. These include but are certainly not limited to:

- Crisis stabilization and resolution
- Inpatient services
- Psychiatric/medical management including medication management and other health services
- Partial care/day treatment
- Social services
- Residential services and supports
- Vocational and educational services and supported employment
- Social and leisure activities

During the 1990's, the number of individuals using community-based mental health and substance abuse services generally increased with only adults with substance abuse problems showing a slight decrease. In fact, in 1990 13,788 persons accessed community-based services for mental health and substance abuse issues. This number climbed to 25,350 individuals by 1999. A further breakdown reveals that in 1990, 6,103 children and adults accessed services at the regional human service centers for substance abuse problems. That same year, 7,685 children and adults accessed human service center services for mental health issues. In contrast, during 1999 there were 6,613 individuals who

accessed substance abuse services while 18,737 individuals accessed mental health services.

CHILD WELFARE AND CHILDREN'S MENTAL HEALTH SYSTEM OF CARE:

During the past decade, both the Child Welfare and Children's Mental Health System of care have been developing community-based alternatives to out-of-home care. The core of these initiatives includes the development of case management systems that use a single plan of care for children. Thus, when children and their families are receiving services from multiple agencies, there would be one plan developed with the family outlining the roles and responsibilities of these agencies in the life of the family. However, much work remains in institutionalizing this approach across all public child-serving agencies.

In North Dakota, there is a single system of foster care for children needing out of home placements. Thus, children from juvenile justice, child welfare and mental health are accessing the same residential treatment centers and/or therapeutic foster homes. In some other States, these services are fragmented with each system setting up their own options for care.

During the past three years, the out-of-home placements in North Dakota have leveled off at approximately 930 youth per month or approximately 1720 unduplicated youth per year.

Children are placed out of home by the court for three possible reasons. They include a court ruling of a) deprivation, b) unruly or c) delinquency. From 1989 to 1999, the number of children placed for unruly behavior remained approximately the same while the number of children referred for deprivation has increased by approximately 60%. During the same period of time, children referred through delinquency actions has more than doubled.

Again comparing 1989 to 1999, the type of placements has remained the same. Family homes continue to provide care for approximate 65% of these children while residential facilities provide care for 35%.

The length of stays in our residential facilities varies from approximately 10.4 months to 4.2 months. Manchester House, with the 4.2-month length of stay, provides care for youth between the ages of 6 and 12. In order to achieve these short lengths of stay, Manchester staff works directly with the community and family to develop a community based plan of care. In addition, staff travels to the child's home community to establish a wraparound plan for the child and the family.

Finally, North Dakota is averaging approximately 35 youth out of state for the past two years. These are children referred to facilities in other states for several reasons, including the out-of state placement is closer to the child's home than the available in-state placement or the services the child need are not provide in-state (services for children with low intelligence and significant emotional disturbances, adolescent sex offenders with lengthy histories and children with unique medical and behavioral issues).

MEDICAID: During the decades of the 1970's and 1980's North Dakota became increasingly dependent on the use of institutional care to deliver long term care services to the citizens of our state. Programs such as Medicaid developed a built-in bias toward institutional care due primarily to the payment mechanism that allowed payment for services received in nursing facilities.

The emphasis began to change somewhat when the federal government authorized States to develop home and community based waivers. The waivers permitted States to provide alternative services that allowed individuals with needs that were normally delivered in nursing facilities to remain in a home or community based setting rather than entering an institution. North Dakota currently operates home and community based waivers for the Elderly and Disabled and Traumatic Brain Injured individuals.

Despite the availability of these waivers, North Dakota in the first half of the 1990's continued to rely heavily on the use of nursing facility care. During that period, about 1.3 percent of our elderly resided in nursing facilities, the highest percentage in the United States. North Dakota supported about 75.6 nursing facility beds per thousand individuals over 65 years of age, whereas the national average was about 50 beds. In 1992, North Dakota had the second highest occupancy rate in the United States at 95.6 percent. During the first half of the decade of the 1990's, Medicaid expenditures for nursing facility care was increasing at almost 10 percent per year.

The Legislative Assembly, Governor Schafer, the Departments of Health and Human Services, concerned citizens and the Long Term Care Industry recognized the need to initiate changes in the way long term care services were being delivered in North Dakota.

Beginning in 1995 a Task Force on Long Term Care Planning has met during the last three interim periods between legislative sessions. The Task Force issued reports in June 1996 and June 1998 that contained dozens of recommendations to the Legislature and the executive branch of government designed to promote and create more community-based alternatives for the delivery of long term care services in North Dakota. A third report is scheduled to be released in October 2000.

Accomplishments

During the past five years steps have been taken to improve the ability of individuals to obtain long term care services in a home or community setting. For example, since 1995 the number of nursing facility beds have been reduced from 7,061 to 6,867, a reduction of 2.7 percent. The percentage of occupied beds has decreased from 6,840 in 1995 to 6,411 in 1999, a reduction of 429 individuals or a 6.3 percent reduction. The percentage of occupied beds decreased from 96.9 percent in 1995 to 93.4 percent in 1999. The number of beds occupied by Medicaid recipients has also declined since 1995 from 3,928 to 3,466 in 1999, a reduction of 11.8 percent. These statistics differ slightly from the data presented during the meetings in August due to the recent availability of updated information.

The growth in expenditures for nursing facility services has decreased dramatically since 1995. The expenditure growth averaged only 2.2 percent during the last four years of the

1990's. The increase was entirely related to nursing facility rates, which increased 6 to 8 percent per year during that period.

North Dakota has encouraged the development of alternatives to nursing facility care by increasing funding for the Elderly and Disabled Medicaid Waiver, the Traumatic Brain Injured Medicaid waiver, Basic Care Assistance Program, Service Payments for the Elderly and Disabled (SPED), and Expanded SPED.

Funds became available in 2000 through the Intergovernmental Transfer Program for providers, including nursing facilities, to receive loans and grants to develop alternatives to nursing facility care. Pilot projects have demonstrated the feasibility of providing quality services for persons with Alzheimer's and Related Dementia.

The North Dakota legislature has established a moratorium -- beginning in 1995 -- on the construction of any new nursing facility beds in the state.

The 2000 report of the Task Force on Long Term Care Planning will include recommendations that a targeted case management option for Medicaid recipients be implemented to ensure that individuals in need of long term care services understand the options that are available to them before making a final decision as to where they choose to receive those services.

The Task Force also recommended the establishment of a rent subsidy program that would be used to supplement low-income individuals in order that they could afford to live in alternative housing rather than be forced to enter a nursing facility.

The Department intends to continue to encourage and support the development of alternatives to nursing facility services. We believe that all individuals and their families need to have adequate information about the availability of long-term care services in order to make an informed decision regarding the type of long-term care services that would best meet their needs. The Task Force on Long Term Care Planning has recommended that an optional Targeted Case Management service be added to the Medicaid State Plan for Medicaid eligible recipients who are elderly or persons with physical disabilities at risk of long-term care services. In addition, the Department still believes that a pre-assessment process should be implemented before individuals are admitted to a nursing facility. The assessment would determine the type of services that an individual requires to meet their long-term care needs and where those services could be obtained including available home and community-based services, if applicable. Persons in need of long-term care and their families would then decide where to obtain the needed services.

AUGUST 2000 OLMSTEAD PUBLIC DIALOGUE MEETINGS: BRIEF SURVEY RESULTS

NOTE: When tabulating the results of the brief survey, responses were grouped in categories to attempt to cluster the information.

Question 1: Please check ALL of the areas or groups where you have a particular interest and/or involvement:

Please Note: Several respondents checked more than one area:

AREA OF INTEREST OR INVOLVEMENT	NUMBER RESPONDED
Persons who have a mental illness	94
Persons who have a developmental disability	88
Persons who are elderly	86
Persons with a physical disability	93
Children with a serious emotional disorder	57

Questions 2: How aware are you of the home and community-based services where you live?

LEVEL OF AWARENESS	NUMBER RESPONDED
Very Aware	86
Somewhat Aware	36
Uninformed	11

Question 3: What kinds of services do you feel are missing where you live?

Please Note: this question elicited many different responses. An attempt has been made to categorize where possible to give a more distinct picture of the needs brought forth by attendees.

SERVICE	NUMBER RESPONDED
Affordable alternative services	16
Affordable, accessible transportation	16
Employment services	16
Case management services	13
Adolescent transitional services	10
Increased Individual Supportive Living Arrangement placement	10
Rural outreach of continuum	10
Transitional living, all populations	9
Guardianship services	8
Psychosocial services/funding	8
Affordable/accessible housing	7
Services for multiple or co-occurring issues	7
Accessible respite care	6
Comprehensive directory of community-based services	6
Trained personal assistants	6
Pretty good services already in place	5
Reduced wait time for psychiatrist appointment	4
Crisis intervention support	3
Adult day care	3
Transitional housing, education, and foster care for young adults	3
Dental/medical care	3
Adaptive devices	3
Unaware of what is missing	3
More representative payees	3
Adult foster care	2
Reservation accessibility of any and all services	2
Alzheimer's care	2
Family support subsidy: child and adult	2
Psychiatric/Chemical Dependency hospitalization in community	2
Transitional support	1

Services for low incidence disabilities	1
Outpatient Serious Mental Illness services	1
Natural/volunteer supports	1
Screening/assessment	1
Parent education for cognitively impaired parents	1
Individual skills training	1
Developmental disabilities safety net	1
Community-based services for vision impaired and deaf	1
Intermediate Care Facility for the Mentally Retarded group homes	1
Clothing vouchers	1
Intensive in-home services	1
Medication support	1
Available American Sign Language interpretation	1
Consumer generated services	1
Foster care	1

Question 4: In your way of thinking, what do you see as an institution?

Note: An attempt has been made to group responses categorically where possible.

Category	NUMBER RESPONDED
Individual perception	43
Any non-family/related residence	28
Developmental Center/ State Hospital	25
Nursing home	13
Group home	10
10+ person facility	7
8+ person facility	6
Prison	5
6+ person facility	2
Assisted living	2
Single purpose by disability housing units/structures	1

AUGUST 2000 OLMSTEAD PUBLIC DIALOGUE MEETINGS: COMMENTS

The following represent the verbal comments and questions received during the Olmstead Workgroup public meetings. These are not exact quotes but rather a paraphrase of the comment or question made.

Region I (Williston) and Region II (Minot, Fort Berthold) Public Meeting Comments

- Increase font size on handouts to accommodate individuals with sight problems.
- How are you reaching people who are living in an institution to obtain their input?
- How do you identify individuals who are unnecessarily institutionalized?
- How are you showing consumers what opportunities are in the community?
- What criteria are used with decision making for individuals who are institutionalized and may not understand their options?
- Have the guardians and family members been consulted concerning the planned movement of 17 individuals out of the institution.
- Is the Anne Carlson Center just a school or an institution?
- What structure is proposed for targeted case management for the elderly and any housing options?
- How do you propose to address the fact that 80% of Medicaid dollars go to institutional care rather than community-based care?
- Important for advocacy groups to partner with State to implement plans for Olmstead.
- Are there consumers on the taskforce (Long-term Care Taskforce)?
- There are no or few community options in the very rural areas of the State for the elderly.
- What is the long-range plan for the Grafton school?
- Is the plan developed for Olmstead the same as the plan for children and foster care?
- There is a state plan on mental health that is reviewed by the mental health planning council. The council has consumers on its roster.

Region III (Devils Lake, Spirit Lake, Turtle Mountain) and Region IV (Grand Forks) Public Meeting Comments

- What is the timeline for the comprehensive Olmstead plan?
- Assisted living home is needed on or close to the reservations. Difficult to find housing on the reservations.
- Why has Department decided not to license assisted living?
- Is there a plan to initiate a waiting list study within the next year?
- Difficult to physically access some businesses for elderly and disabled. Why hasn't someone done something about this issue?
- There will be a meeting in Devils Lake to discuss access issues.
- What happens under Olmstead if a consumer wants to stay in the institution but the treating professionals believe that they should no longer be in the institution?

- Is there anything in place to help people integrate into employment? Can VR services look outside the region or nationally? Once integrated into the community, are there services to help move a person from group living to independent living? If a person is doing well, will services still be available to help people? Will litigation help to define what the Supreme Court didn't define?
- It is important to make sure there are community supports in place before you move away from institutional services.
- What are you doing to educate people concerning ADA?
- Important to continue working on support services such as psychosocial rehabilitation centers.
- Has the Olmstead workgroup addressed need for additional funding to create additional support services to move people from nursing homes and the Developmental Center?
- Is there a timeframe for the workgroup to develop a plan and will this be completed prior to the legislative session?
- Because of the need to pay a co-pay for services and a lack of a job, I only have about ten dollars per week to live on. What do I do?
- What happens if a plan is not developed?
- Devils Lake residents strongly urge you to follow through with assisted living.
- There is a need for funding for home modification to allow people to remain in their home. There is a need for more consumer directed services.
- Has there been any thought given to medical assistance for people with disabilities?
- How will the white paper be made available to the public?

Region V (Fargo, Wahpeton) and Region VI (Jamestown, Valley City) Public Meeting Comments

- Challenge everyone to use People First language.
- Where is the State of North Dakota in the Olmstead planning process?
- We need to make sure we are meeting the needs of deaf disabled people. Need to get more people who are deaf and have a disability out into the community. Need to make sure we have enough interpreters for people with developmental disabilities. In the deaf community, it is acceptable to say "this is a deaf person" when referring to a person in the deaf community rather than "hearing impaired."
- Stigma doesn't go away with a change in language.
- Concerned that de-institutionalizing may actually cause more dependence on the system. Mainstreaming can actually cause additional isolation.
- Previously unaware of any waiting lists for services. What type of waiting lists are out there?
- Not enough programs for people who are de-institutionalized.
- People who use American Sign Language have unique needs. You need to understand their culture before you can successfully work with them.
- Is there a specific date that an Olmstead Plan will be in place.
- The most integrated setting may lead to more institutionalization rather than less.
- It is difficult to interpret what least restrictive environment actually is.
- There is a concern regarding individuals who need more structured care than Basic Care but do not qualify for higher level nursing care.
- Encourage the State to provide more education to providers concerning the Olmstead Act. What are other States doing relative to the Olmstead Act?

- At what point will the State of North Dakota interact with other States concerning Olmstead?
- How well do the agencies involved in the workgroup work together for individuals who have many different needs and how can we improve that collaboration?

Region VII (Bismarck, Standing Rock) and Region VIII (Dickinson) Public Meeting Comments

- Number of families being served is rising but funding is not, resulting in families not receiving the level of services needed.
- What timeframe does the workgroup have for implementing the Olmstead plan? Will advocacy groups be involved and when will that occur?
- Lower cost programs with no Federal funding in the past have been cut and how does the Department feel about that? Guardianship programs are needed for individuals with serious mental illness and how does the Department feel about that issue?
- The ARC of the United States survey sent to all Medicaid directors lists North Dakota as poor regarding services indicating that there are gaps in services. It indicated that North Dakota does not maintain waiting lists. What does the group think of this?
- How do you keep track of unmet needs? How do you identify people who are at risk of institutionalization because of lack of available services?
- Will funding follow the consumer into the community? Are there actually 20% of nursing home residents who do not actually need to be there?
- A challenge is to pay caregivers at a level that will encourage them to make a career out of it.
- How do you track individuals who live independently and chose to pay for housing rather than medication because of limited resources?
- If a service provider refuses to provide the service to a consumer, what other options do you have?
- Will anything be prepared for the Legislature concerning Olmstead and have budgets been built in the Department to address issues surrounding Olmstead?
- What are you going to do to improve the quality of services provided?
- Will the Department involve HCFA with the planning for Olmstead?

RECOMMENDATIONS

- Request to the Governor to appoint a commission to provide the North Dakota definitions inherent to the Olmstead decision and to develop a comprehensive State Plan. This commission would consist of a representative from the Governor's Office, legislators, family members, consumers, advocates, providers, and State agency heads. Federal agencies will be available for consultation as appropriate (See Appendix II – Letter of Support).
- The Department of Human Services should schedule regular information/discussion sessions with regional stakeholders surrounding community-based services for persons with disabilities.
- The Department of Human Services should take the lead to develop a pre-assessment screening process that must be completed prior to admission to a nursing facility. This screening process would determine care needs and identify where the services necessary to meet those needs could be obtained. This would help to ensure that persons in need of long-term care services and their families can make informed decisions regarding where they wish to obtain needed services.
- The Department should continue to encourage and support the development of alternatives to nursing facility services.

APPENDIX I

WORKGROUP MEMBERSHIP

Melissa Hauer – Legal Services

Mark Kolling – Division of Disability Services, Developmental Disabilities Unit

Karen Romig Larson – Division of Mental Health and Substance Abuse Services

Paul Ronningen – Division of Children and Family Services

Marilyn Rudolph – Northwest Human Service Center

Alex Schweitzer – North Dakota State Hospital and North Dakota Developmental Center

Linda Wright – Division of Aging Services

Dave Zentner – Medicaid

APPENDIX II



Protection and Advocacy Project

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October 9, 2000

Mark Kolling
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DEPT. OF HUMAN SERVICES

OCT 19 2000

DISABILITY SER. DIV.

Dear Mark:

The public forums held in August were a positive step toward including interested individuals in the development of the state's Olmstead plan. People gave feedback that we hope has been helpful to the Department.

Development of an effective plan will require participation from key stakeholders. Yvonne Smith stated at the public forum that the Department of Human Services would seek this participation. We ask that you include People First of ND, the Centers for Independent Living, the Mental Health Association, the ARC, the AARP, the Federation of Families, and Protection and Advocacy in your planning process.

We thank the Department's for its commitment to integrate individuals with disabilities into the community and look forward to working with the Department to further that goal.

Sincerely,

Raylynn Lauderdale

Corinne Hofmann
Protection and Advocacy

Raylynn Lauderdale
People First of ND

Dianne Sheppard
ARC - Upper Valley

Corinne Hofmann
Rose Stoller
Rose Stoller
Mental Health Assoc.

Dianne Sheppard

Randy Sorenson
Options BCIL

Chuck Stebbins
Dakota CIL

Randy Sorenson

Chuck Stebbins

Norm Stuhlmiller
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Amanda Ghauri
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